

**Children's Special Health Services
Family Advisory Council meeting minutes
February 26, 2005**

Present from Family Advisory Council: Donene Feist (phone), Jennifer Restemayer, Lisa Beckman, Lori Hanson, Twyla Bohl,

Present from CSHS: Terry Bohn, Tammy Gallup-Millner, Sue Burns, Leann Bayman, Kora Dockter, Dr. Wentz

Department of Health Representative: Kim Senn

Guests: Michele Keller

Follow up from previous meeting

- There were no changes suggested to the November 2004 meeting minutes
- The Review/Recommendation form was passed around. No changes were suggested.
- Membership terms for five of the members will expire effective with the May meeting. Twyla and Jennifer agreed to serve an additional two-era term. Teri Walters communicated that she did not want to continue on the Council and a replacement will be recruited. Follow-up will be made with Carla and Evelyn.

CSHS program updates

- First Sounds Project: Sue reported that a new hearing grant will focus on tracking to audiologist and other follow up services. She will be attending a national conference in March.

Medical Home Catch Grant meetings

- Two meetings have been held: in Bismarck for families and in Jamestown for providers. Another meeting is planned for Bottineau in early March. An application for a presentation has been submitted for the Family Connections Conference in June.

Metabolic Foods

- The newborn screening may expand to cystic fibrosis. Pediatricians surveyed supported screening for this condition. A pilot may begin this summer and go for 9 months. The cost of the screening is \$8-9. ND is one of five states that screens for 35-40 conditions. National recommendations are forthcoming.

Specialty care program

- The Family Handbook will be distributed when financial eligibility forms are due. The Handbook is also on the web.

County directors meeting

- Tammy summarized some of the issues that were discussed during a recent meeting with county social service directors

Medical needs task force meeting

- Interagency group looking at the medical needs of kids. May apply for Katie Beckett waiver (to gap fill). Attempting to identify medically fragile kids – getting definitions. Terry represents CSHS on the task force. Donene and Jennifer attended the last meeting.

Pediatric Service task Force

- The next meeting of this group is scheduled for the end of March. Twyla described some issues with county case management she would like discussed at a future meeting.

Contracts/RFP

- CSHS will be using a new RFP process developed in DHS. Need to wait to see about available funding until after the legislative session is over.

MCH Block Grant

- ND received flat funding for the fiscal year 2005 budget

Legislative Update

- HB 1012 is the DHS budget bill. The legislative request was for flat funding for the CSHS program. So far no changes have been discussed.
- SB 2163 – related to allowing children to carry medicine for their asthma in school – is expected to pass.
- SB 2395 – Treatment for child with Russell-Silver syndrome. This bill has been amended to include a Medicaid waiver, study resolution, and emergency clause.
- HCR3054 – a study – passed

Emergency Medical Services for Children (EMSC)

- Michele Keller, with the EMSC in the ND Department of Health, provided an overview of the program. Three suggestions were mentioned.
 1. Do a presentation on EMSC at the Family Connections Conference
 2. Good progress had been made in incorporating emergency issued specific to CSHCN into training.
 3. Add CSHCN specific goals and objectives in the new grant cycle.

CSHS Needs Assessment

- A handout was passed out summarizing the needs assessment process including the three topic areas that will be developed into state performance measures for the CSHCN population. For each of the three priority needs, members were asked to discuss:
 1. What can be done to impact the need? (i.e. activities, strategies) and

2. How can the need be measured? (how do you know if it's getting better/improving)

Members offered the following suggestions/thoughts

* Increased information & awareness of services

- Outreach to new mothers
- Need info when you need it/seek it
- Work to increase partner's knowledge
- Fill brochures at clinic racks
- Posters in waiting rooms, etc.
- Help families get what they need – documentation requirements
- Use technology to help families get info.
- Laminated cards with info.
- Face to face contact often necessary
- Grand Rounds – good if pediatric case study focused
- Do outreach to get info to new MA providers

* Geographic access to specialty care

- Goal of access is four quadrants of the state
- Sometimes access in 1 location all that can be achieved
- Extended hours for clinics (emergency room misuse)
- Measurement: how long after diagnosis did you find out about us?

* Extra-ordinary medical needs

- Gap kids
- Need to define extra-ordinary
- Respite care
- Budget?

Other

- Cover Healthy North Dakota and PRAMS at the next meeting

Next Meeting

- Saturday May 21, 2005, 1:00 –3:30 pm